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# Testing carer skill training programs in Spanish carers of patients with eating disorders

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## Abstract

**Background:** The aim of this research was to conduct a pilot study to measure the effectiveness of the Collaborative Care Skills Training Workshops (CCSTW) on the outcomes of Spanish carers and to analyse the impact of this programme on the patient's wellbeing. We used psychoeducation as a comparison intervention in the study. **Method:** The study compared two forms of carer workshops. 64 carers and 37 eating disorder patients participated in this study. Carers were randomised to either the CCSTW or the Psycho-educational programme. This study used an experimental intervention design with evaluations before, after and at a 3-month follow-up. **Results:** Carers receiving both intervention programmes showed an improvement in wellbeing indicating a benefit from the training. The course of burden, psychological distress, expressed emotion and illness perception was similar in the two groups. In patients whose caregivers had participated in CCSTW programme the levels of anxiety, depression and psychological distress decreased. **Conclusions:** These findings suggest that carer distress, burden, illness perception and expressed emotion can be alleviated if they are helped in this role. There appear to be secondary benefits of the CCSTW on patients' wellbeing.

***Keywords:*** Carers, eating disorders, skills-based workshops, pilot study.

## Resumen

***Aplicación de programas de entrenamiento en habilidades para cuidadores españoles de pacientes con un trastorno de la conducta alimentaria.*** **Antecedentes:** el objetivo de esta investigación fue llevar a cabo un estudio piloto para evaluar la efectividad de los Talleres de Cuidado Colaborativo (CCSTW) en cuidadores españoles de pacientes con un trastorno alimentario y analizar el impacto de este programa en el bienestar del paciente. **Método:** este estudio comparó dos programas para cuidadores. Los cuidadores fueron asignados aleatoriamente a un programa psicoeducativo o a CCSTW. Participaron 64 cuidadores y 37 pacientes con un trastorno alimentario. Este estudio utilizó un diseño experimental con medidas pre-post y a los 3 meses de seguimiento. **Resultados:** los cuidadores de ambos programas mostraron una mejora en el bienestar que indica el beneficio de ambas intervenciones. La evolución de la carga del cuidador, el malestar psicológico, la emoción expresada y la percepción de la enfermedad fueron similares en los dos grupos. En los pacientes, cuyos cuidadores habían participado en el programa CCSTW, los niveles de ansiedad, depresión y malestar psicológico disminuyeron. **Conclusión:** estos resultados sugieren que el malestar del cuidador, la carga, la percepción de enfermedad y la emoción expresada pueden aliviarse si se les ayuda en este rol. Se encuentran beneficios secundarios de los CCSTW en el bienestar de los pacientes.

***Palabras clave:*** cuidadores, trastornos alimentarios, entrenamiento en habilidades, estudio piloto.

Eating Disorders (ED) are serious and potentially life-threatening illnesses that affect the physical, emotional, and social development of those suffering from the condition. Taking care of someone with ED can produce considerable stress and strain on family functioning. It can also generate a number of dysfunctional changes in the family organization and interactions (Coomber & King, 2013; MacDonald, Murray, Goddard, & Treasure, 2010). Two systematic reviews have highlighted how the problems associated with this illness impact negatively on the quality of life of all family members in terms of burden, distress, accommodating and enabling behaviours and expressed emotion (Anastasiadou, Medina-Pradas, Sepúlveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009).

These results advocate the active involvement of family members in the treatment process, which has led to the development of a variety of interventions for this purpose. These interventions aim to help caregivers of people with an eating disorder to either cope with the burden and distress that commonly accompanies this role or to make them more effective at providing support (Hibbs, Rhind, Leppanen, & Treasure, 2015). In a recent study, evaluating the literature on carers/parenting interventions for people with eating disorders, Treasure and Palazzo (2016), concluded that: a variety of psycho-educational interventions can improve carer

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coping; family based therapy successfully teaches skills to manage behaviours present in the early phase of the illness; and concluded that the New Maudsley, the approach that we used in this research, addresses how to maintain some of the interpersonal behaviours.

The New Maudsley approach was developed by Treasure and colleagues (2007). They created a skills training course ''the Maudsley eating disorder collaborative care skills workshops'' (CCSTW) for family members caring for individuals with all forms of eating disorders. In essence, these workshops teach carers how to moderate their expressed emotion and match their goals and expectations with the sufferers' stage of change (Prochaska & DiClemente, 1992). Carers are also taught the principles of motivational interviewing to improve communication and set a positive context for change. The workshops curriculum includes how to undertake a functional analysis of problematic behaviours, and to use problem solving strategies, behavioural experiments and goal setting to foster change (Sepulveda, Lopez, Whitaker, & Treasure, 2008a; Treasure et al., 2007). These workshops were designed to equip carers with the skills and knowledge needed to be an expert carer and help the person with an eating disorder break free from the traps that block recovery. It is important to indicate that the interpersonal component of the maintenance model of anorexia developed by Schmidt and Treasure (2006) showed that carers' distress is linked to patient distress, which in turn is linked to ED symptoms (Treasure et al., 2008). What is inferred from this model is that if carers improve their strategies for dealing with the problem, for expressing less emotion, and better understand what they can do in each phase of the illness, they will feel better and this will also have an impact on the patient's symptomatology itself.

While the content of the workshops has been disseminated throughout the United Kingdom and Australia, its evaluation is limited to few studies. A non-experimental research design with repeated measures was implemented by Pepin and King (2013) with 15 Australian carers. This study showed that participation led to significant reductions in carers' reported expressed emotion, dysfunctional coping, distress and burden which were maintained at the 8-week follow-up. In a group of 35 British carers, participation in these workshops reduced distress, level of general burden and perceived impact of eating disorder symptoms (Sepúlveda et al., 2008a). This pilot study used an experimental intervention with a before-after-and-3-month follow-up design. In a prospective follow-up study involving 47 carers, participation in the workshops led to reductions in levels of expressed emotions in post-intervention (Sepulveda, Todd, Whitaker, Gover, Stahl, & Treasure, 2010). However, none of these studies analysed the impact of these interventions on caregivers in the patients themselves.

Therefore, the general aim of this research was to conduct a pilot study to measure the effectiveness of the CCSTW on the outcomes of Spanish carers. We used psychoeducation as a comparison intervention in the study, as psychoeducational programmes have also shown their efficacy in intervention with relatives of patients with eating disorders (Gutierrez, Sepúlveda, Anastasiadou, & Medina-Pradas, 2014; Uehara, Kawashima, Goto, Tasaky, & Someya, 2011). The psycho-educational programme that we used was based on the programme by Fairburn et al. (2009) and we added coping skill contents. We are also interested in knowing if changes in caregivers also have an impact on the patient's well-being. Therefore, the specific objectives were: (i) to compare the effectiveness of the CCSTW with a psycho-educational programme, and (ii) to analyse the impact of both programmes on the patient's wellbeing.

It was hypothesized that CCSTW would have better results than psycho-educational programme in terms of carers' expressed emotion, dysfunctional coping and distress.

## Method

### *Participants*

Carers were recruited from the Eating Disorder Unit of a public Hospital in the province of Alicante (Spain). To be eligible for this study, the carers had to be currently living with a person with an eating disorder, who was also invited to participate in the evaluation process. Carers were excluded from the study if they had a psychiatric pathology or the patient that they cared for had a borderline personality disorder, was suffering from psychosis, was alcohol or substance dependent or had a coexisting serious medical condition. Patients were included in the study if they were outpatients and were living with their parents. Exclusion criteria were: borderline personality disorder, psychosis, current alcohol or substance dependence, serious medical condition or parental psychiatric pathology. This information was provided by the Eating Disorder Unit.

The sample of carers consisted of 64 participants, with an average sample age of 48.46 (SD = 8.00), 40.6% were male and 59.4% female. 59.4% were patients' mothers, 32.8% their fathers, 3.1% their partners and 4.7% their siblings. 82.8% of the carers lived with the patients. 68.8% were employed and 82.8% were married.

*Table 1*
Demographic and psychosocial variables of the carers at baseline

| Carers | Total Group N = 64 | CCSTW n= 40 | Psychoeducation programme n= 24 | |
|---|---|---|---|---|
| Gender | | | | |
| Male | 40.6% | 45% | 33.3% | F =0.83 |
| Female | 59.4% | 55% | 66.7% | p = .36 |
| Age | M = 48.46 SD = 8.00 | M = 48.45 SD =7.54 | M = 48.50 SD = 8.89 | t = -.24 p = .98 |
| Living with the sufferer | 90.3% | 92.3% | 87% | F =0.4 p = .49 |
| Employment status | | | | |
| Employed | 68.8% | 72.5% | 62.5% | |
| Unemployed | 7.8% | 10% | 4.2% | F =1.73 |
| Housewife | 20.3% | 15% | 29.2% | p = .19 |
| Other | 3.1% | 2.5% | 4.2% | |
| Educational status | | | | |
| First level | 18.8% | 17.5% | 20.8% | |
| Second level | 29.7% | 35% | 20.8% | F =0.22 |
| Third level | 19.3% | 12.5% | 33.4% | p = .64 |
| University degree | 31.3% | 35% | 25% | |
| Marital status | | | | |
| Married/living together | 82.8% | 90% | 70.8% | F =3.99 p = .06 |
| Relationship with the sufferer | | | | |
| Mother | 59.4% | 55% | 66.7% | |
| Father | 32.8% | 40% | 20.8% | |
| Sibling | 4.7% | 2.5% | 3.7% | F= 3.19 |
| Partner | 3.1% | 2.5% | 4.2% | p = .07 |

Thirty-seven eating disorder patients participated in this study. Patients were 91.9% females with a mean age of 20 (SD = 6.78). 75.7% were diagnosed with AN, 13.5% BN and 10.8% with an unspecified eating disorder. The mean duration of the illness was 57.21 months (SD = 61.48). 76.7% had been admitted to the Eating Disorders Unit, but when this research was carried out they were outpatients. 93.3% were receiving psychological treatment and 50% were receiving pharmacological treatment.

Demographic data on carers and details about the person with an eating disorder are shown in Table 1 and Table 2. As expected at baseline there were no differences between the carers and patients allocated to the two groups.

*Instruments*

*Carers*

Clinical and socio-demographic data: carers completed a demographic questionnaire that included details about themselves (including age, gender, marital status, employment status and education level).

The Hospital Anxiety and Depression Scale (HADS) (Terol, López-Roig, Rodríguez-Marín, Martín-Aragón, Pastor, & Reig, 2007; Zigmond & Snaith, 1983) is a 14-item instrument designed to detect the presence and severity of anxiety and depression. In this study, the Cronbach alpha coefficient was .86 for each subscale.

General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988). The GHQ-12 was used to measure carers' level of psychological distress. Each item is rated on a 4-point scale with scores ranging from 0-36, with higher scores indicating increased psychological distress. The Spanish version has been validated with a satisfactory internal consistency (Cronbach alpha of .76) (Rocha, Pérez, Rodríguez-Sanz, Borrell, & Obiols, 2011). The Cronbach alpha coefficient was .90 in this study.

*Table 2*
Demographic, clinical and psychosocial variables of the patients at baseline

| Patients | Total group N= 37 | CCSTW n= 23 | Psychoeducation programme n= 14 | |
|---|---|---|---|---|
| Gender | | | | |
| Male | 8.1% | 13% | 0% | F = 1.98 |
| Female | 91.9% | 87% | 100% | p = .16 |
| Age | M = 20<br>SD = 6.78 | M = 19.17<br>SD =5.78 | M = 21.35<br>SD =8.22 | t = -.95<br>p = .35 |
| Illness duration | M = 57.21months<br>SD = 61.48 | M = 47.69<br>SD=53.65 | M = 72.85<br>SD =7.91 | t = -1.21<br>p = .23 |
| Diagnosis | | | | |
| Anorexia | 75.7% | 65.2% | 92.9% | F = 3.96<br>p = .06 |
| Bulimia | 13.5% | 17.3% | 7.1% | |
| EDNOS | 10.8% | 14.3% | 0% | |
| Previous inpatient | 76.7% | 73.7% | 81.8% | F = 2.37<br>p = .13 |
| Psychological treatment | 93.3% | 94.7% | 90.9% | F = 0.15<br>p = .69 |
| Pharmacotherapy | 50% | 52.6% | 45.5.5 | F = 0.13<br>p = .71 |
| Symptomatology (EAT-26) | M = 33.44<br>SD = 18.21 | M = 35.9<br>SD =19.68 | M = 30.37<br>SD =16.97 | F = 0.39<br>p = .54 |

Family Questionnaire (FQ) (Wiedemann, Raiky, Feinstein, & Hahlweg, 2002; Sepúlveda et al., 2014): the FQ consists of 20 items measuring expressed emotion (EE), (10 for criticism (CC) and 10 for emotional over-involvement (EOI). Scoring ranges from 1 as "never/rarely" to 4 as "very often" and a higher total score indicates higher expressed emotion. In this study we obtained a satisfactory internal consistency of 0.80 for the EOI subscale, and 0.82 for the CC subscale.

Level of Expressed Emotion (LEE) (Cole & Kazarian, 1988). The LEE is a 60-item self-report instrument with a true/false scale which is based on the theoretical dimensions of EE. The Spanish version subscales are: Attitude toward the illness, intrusiveness, hostility toward the patient and tolerance or coping with the illness (Sepúlveda, Anastasiadou, del Río, & Grael, 2012). In this study internal consistency ranged from 0.60 to 0.75.

Accomodation and Enabling Scale for Eating Disorders (AESED) (Sepulveda, Kyriacou, & Treasure, 2009). The AESED was designed to measure accommodation and enabling behaviours by families of people with eating disorders. The instrument has 33 items and five factors: Avoidance and Modifying Routine; Reassurance Seeking; Meal Context Ritual; Control of Family; and Turning a Blind Eye. We used the Spanish version of this questionnaire which was adapted and validated by our team and Cronbach's alpha ranged from 0.79 to 0.89 (Quiles, Quiles, Pamies, Sepúlveda, & Treasure, 2016).

Eating Disorders Symptom Impact Scale (EDSIS) (Carral-Fernández, Sepulveda, Gómez del Barrio, Graell, & Treasure, 2013; Sepulveda, Whitney, Hankins, & Treasure, 2008b). The EDSIS measures the specific burden experienced by carers and assesses their perceptions of the emotional, psychological and tangible impact of caring for someone with ED. The EDSIS comprises of four subscales (nutritional difficulties, guilt, manifestation of dysregulated behaviour and social isolation) with a total of 30 items answered on a 5-point Likert scale (0 = ''Never'', 4 = ''Nearly Always''). In this study internal consistency ranged from 0.62 to 0.85.

Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006; Pacheco-Huergo et al., 2012). The Brief IPQ has nine items and all of them except the causal question are rated using a 0-to-10 response scale. Five of the items assess cognitive illness representations: consequences, timeline, personal control, treatment control, and identity. Two of the items assess emotional representations: concerns and emotions. One item assesses illness comprehensibility. In this study, the Cronbach alpha coefficient was .71.

*Patients*

In addition to the demographic and clinical data, self-reported measures were used to assess psychological distress and expressed emotion. The self-reported measures were: the General Health Questionnaire-12 (GHQ) and the Hospital Anxiety and Depression Scale (HADS), both of which have been described above.

*Procedure*

*Design*

The research compared two carer skills workshops: CCSTW and a psycho-educational programme.

Figure 1 shows the CONSORT diagram for the study. At the time of the recruitment for this project, the Eating Disorders Unit Carers database consisted of 137 carers. Parents who confirmed interest and willingness to participate and met inclusion criteria were randomly assigned to the two groups. A research administrator independent of the clinicians involved in the assessment and in the treatment used a computer generated randomisation process.

Eighty-two carers agreed to participate in the programme and were randomised to either the CCSTW or the psycho-educational programme. However, eighteen of them (n = 16 psycho-educational and n = 2 CCSTW) did not attend any session even though they agreed to participate. This failure to engage may be because people in the psycho-educational programme had longer waiting times. Therefore 64 carers finally participated (n = 40 in CCSTW and n = 24 in psycho-educational programme).

With respect to the patients, 37 initially agreed to participate (n= 23 patients whose carers participated in CCSTW and n = 14 patients whose parents participated in the psycho-educational programme). Questionnaire completion rates were: 78.26% in T2 and 47.8% in T3 for patients whose carers participated in CCSTW and 71.4% in T2 and 57.14% in T3 for patients whose carers participated in psycho-educational programme.

This study used an experimental intervention design with before-after-and-3-month follow-up. Thus, carers completed self-report questionnaires at baseline (T1) (just before the start of the intervention), at the end of the intervention (T2) and 3 months after the last workshop (T3).

The patients themselves did not participate in any type of intervention. They were only asked to complete the battery of questions at the same time intervals as the carers were assessed,

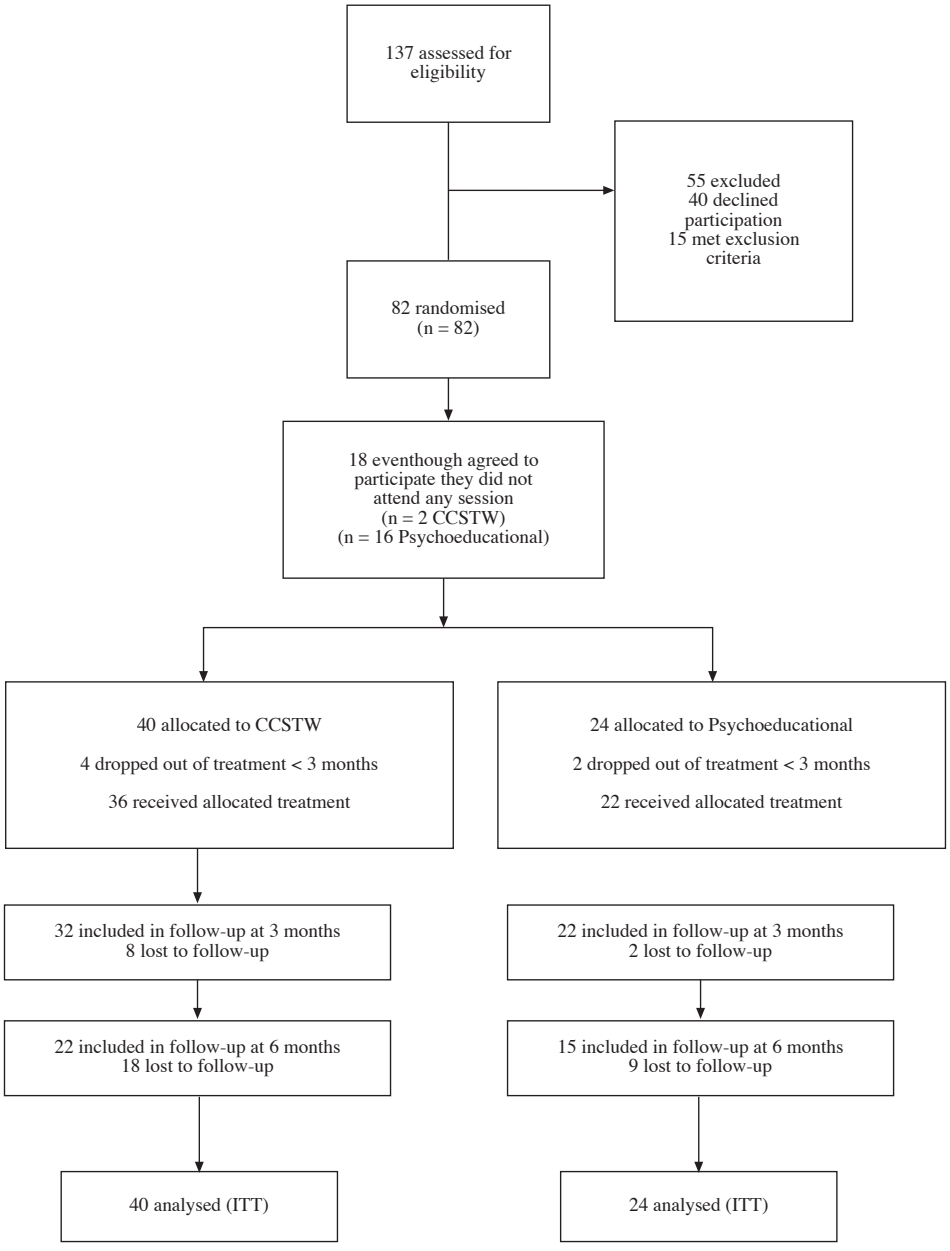


**Figure 1.** CONSORT diagram

at baseline (T1) (just before their carers started the intervention), at the end of the intervention (T2) and 3 months after the last workshop (T3).

*Interventions*

Both programmes consisted of a total of six workshops, spanning a 3-month period and a final follow-up workshop. Each workshop lasted 2 hours, and the additional follow-up session was held at 3 months post-intervention. An outline of the content of each programme is given in Table 3.

CCSTW programme was translated by two clinical experts trained in the principles of this intervention, who reached a consensual translation which was revised by an experienced bilingual clinical expert.

Each programme was carried out by a different psychologist, both belonging to the research group. The psychologist who carried out the CCSTW programme had received training from the original authors of this programme.

*Table 3*
Contents of CCSTW and psychoeducational programme

| PROGRAMME | |
|---|---|
| | **CCSTW** |
| WORKSHOP 1 | Description of the model of carer strain and stress in ED. Description of the Maudsley maintenance model of ED |
| WORKSHOP 2 | Understanding relationship patterns: the over protective or the over directive approach. How to step back and provide warmth and guidance<br>Listening strategies: basic motivational interviewing |
| WORKSHOP 3 | Introduction to the transtheoretical model of change<br>Practice in communication skills |
| WORKSHOP 4 | Advanced motivational interviewing skills: managing resistance and eliciting "change talk".<br>Role playing: managing resistance |
| WORKSHOP 5 | Introduction to the concept of functional analysis of problematic behaviours. The skills of problem solving and goal setting |
| WORKSHOP 6 | Review: what we have learnt, managing own emotions, managing relationships, etc. Further practice |
| FOLLOW-UP | Review of communication, coping and relationship skills in practice |
| **PSYCHOEDUCATIONAL PROGRAMME** | |
| WORKSHOP 1 | Information about ED: Characteristics, consequences and prevalence |
| WORKSHOP 2 | Information about ED: precipitating, predisposing and maintaining factors |
| WORKSHOP 3 | Stress, dimensions of stress response and consequences. Stress control strategies: breathing and relaxation exercises. Training |
| WORKSHOP 4 | Distorted thoughts: The A-B-C model. Beck's cognitive distortions. Strategies to control and modify these thoughts |
| WORKSHOP 5 | Self-esteem. Strategies to improve self-esteem |
| WORKSHOP 6 | Problem solving. Review: what we have learnt |
| FOLLOW-UP | Review of information about ED, stress, distorted thoughts, self-esteem and problem solving |

Note: CCSTW programme adapted of "An examination of the impact of the Maudsley eating disorder collaborative care skills workshops on the well being of carers. A pilot study" de Sepulveda, A. R., Lopez, C., Whitaker, W., & Treasure, J. (2008). Social Psychiatry and Psychiatric Epidemiology, 43, 584-591

*Ethical considerations*

Approval for the study was given by the Ethics Committee of the San Juan Hospital and the Ethics Committee of the University Miguel Hernández (R-12/312). Carers and patients were provided with a written explanation of the study and written informed consent was obtained from all of them. Participants were not offered any incentives for their participation.

*Data analysis*

Independent research assessors, who were blind to the treatment allocations, conducted pre-randomisation evaluations (baseline), at 3 months (end of the treatment) and 3 months after the last workshop.

We used IBM SPSS Statistics 22.0. All formal statistical analyses were based on an intent-to-treat principle with all participants analysed in the treatment arm to which they were assigned. The three evaluations (baseline, at the end of the treatment and 3 months post treatment) were based upon intention-to-treat. Missing data for both of the groups were imputed using multiple imputation based on fully conditional Markov chain Monte Carlo (Schaefer, 1997). In both groups, it was proved that all the missing data were Missing Completely at Random (MCAR) because the Roderick Little test was not significant in any case. As a result, the final analyses were based on the pooled results of 5 separate imputations.

Data were analysed by conducting repeated ANOVAS to determine the level of change over time and determine the effect of participating in the workshops on carers' psychological distress, levels of expressed emotion, carer burden, accommodation and enabling behaviours and their illness perception. Pairwise comparisons were performed following a significant main effect of time (Bonferroni's test). One way analysis of variance or independent samples median tests (continuous data) were used to compare data at one time point.

No formal sample size calculation was undertaken, since this is a pilot study and we are interested in estimating effect sizes. Effect sizes were calculated using partial eta squared. Partial eta-squared indicates the percentage of variance in the dependent variable attributable to a particular independent variable. A commonly used interpretation is to refer to effect sizes as small ($\eta = 0.2$), medium ($\eta = 0.5$), and large ($\eta = 0.8$) based on benchmarks suggested by Cohen (1988).

## Results

*CCSTW: changes in carers and patients*

In table 4 we present the means and standard deviations for the measures at baseline (T1), post-workshops (T2) and at three months follow-up (T3) for this group of carers.

Psychological distress experienced by carers, as measured by the GHQ-12, showed a significant decrease over time. The same occurred with depression, evaluated with the HADS, which decreased after having finished the programmes. However, both

effect sizes were small. There was not a significant reduction in anxiety, evaluated with the HADS.

Expressed emotion was evaluated using two questionnaires, the FQ and the LEE. Carers' level of emotional over-involvement (ŋ = .50) and critical comments (ŋ = .24) revealed a significant reduction from T1 to T2 and from T2 to T3. With respect to the results of the LEE, total scores of this questionnaire presented a significant decrease from T1 to T2, and the effect size was moderate (ŋ = .48).

Accommodation and enabling behaviours (AESED) total score, showed a significant decrease from T1 to T3 (ŋ = .21).

There was a reduction in care giver burden, total score of the EDSIS presented a significant decrease from T1 to T3 and from T2 to T3 (ŋ = .47). In particular, there was a significant reduction

*Table 4*
CCSTW group: means and standard deviations for the measures at baseline (T1), post- intervention (T2) and at three months follow-up (T3)

| | Baseline T1 M (SD) | Post-intervention T2 M (SD) | Follow-up T3 M (SD) | F | p | Bonferroni post-hoc | Effect Size ŋ |
|---|---|---|---|---|---|---|---|
| HAD | | | | | | | |
| Anxiety | 9.22 (4.75) | 8.20 (4.34) | 8.25 (2.39) | 1.69 | .198 | – | – |
| Depression | 6.57 (4.31) | 5.75 (4.07) | 5.54 (4.22) | 3.38 | .045 | T1>T2 | 0.14 |
| GHQ-12 | 15.55 (7.04) | 11.80 (6.41) | 14.96 (7.39) | 3.87 | .029 | T1>T2 | 0.16 |
| FQ: EOI | 18.05 (4.88) | 16.27 (4.32) | 13.91 (5.12) | 19.08 | .000 | T1>T3; T2>T3 | 0.50 |
| FQ: CC | 13.38 (6.40) | 11.25 (5.39) | 9.65 (4.55) | 6.26 | .004 | T1>T3; T2>T3 | 0.24 |
| LEE | | | | | | | |
| Attitude illness | 1.86 (2.80) | 1.11 (2.00) | 1.35 (1.83) | 3.98 | .027 | T2<T3 | 0.17 |
| Intrusiveness | 3.34 (2.10) | 2.82 (1.79) | 2.96 (1.90) | 1.52 | .231 | – | – |
| Hostility | 3.73 (4.11) | 2.55 (2.99) | 3.29 (2.91) | 10.32 | .000 | T1>T2 | 0.35 |
| Tolerance | 3.97 (2.35) | 3.25 (2.41) | 2.74 (2.14) | 4.49 | .017 | T1>T3 | 0.19 |
| Total | 10.56 (6.51) | 6.81 (5.01) | 7.68 (6.03) | 6.70 | .009 | T1>T2 | 0.48 |
| AESED | | | | | | | |
| Meal ritual | 3.45 (4.66) | 2.61 (3.39) | 1.49 (1.50) | 6.23 | .004 | T1>T3 | 0.26 |
| Control | 12.10 (6.50) | 9.49 (5.22) | 9.53 (4.50) | 5.98 | .005 | T1>T2; T1>T3 | 0.25 |
| Reassurance | 8.68 (7.20) | 7.68 (6.07) | 7.12 (4.00) | 0.93 | .403 | – | – |
| Turning | 1.37 (1.77) | 1.52 (1.91) | 1.72 (1.67) | 0.45 | .641 | – | – |
| Avoidance | 12.58 (8.70) | 9.96 (7.07) | 9.27 (5.05) | 3.83 | .030 | T1>T3 | 0.18 |
| Total | 36.70 (21.05) | 30.97 (16.29) | 28.53 (13.90) | 4.30 | .022 | T1>T3 | 0.21 |
| EDSIS | | | | | | | |
| Nutritional | 11.96 (6.62) | 10.22 (7.28) | 6.00 (4.11) | 16.20 | .000 | T1>T2; T1>T3 | 0.81 |
| Guilt | 8.73 (5.61) | 7.98 (4.21) | 6.92 (5.43) | 3.69 | .034 | T1>T3 | 0.16 |
| Dysregulated | 5.43 (5.55) | 4.53 (3.99) | 3.71 (2.76) | 3.79 | .061 | T1>T3 | – |
| Isolation | 6.81 (4.05) | 5.35 (3.57) | 6.05 (5.21) | 3.21 | .033 | T1>T2 | 0.14 |
| Total | 32.87 (15.72) | 26.15 (13.19) | 19.29 (13.76) | 16.24 | .000 | T1>T3; T2>T3 | 0.47 |
| BIPQ | | | | | | | |
| Consequences | 7.11 (2.03) | 4.97 (2.20) | 5.38 (1.96) | 15.15 | .000 | T1>T2; T1>T3 | 0.93 |
| Duration | 6.61 (2.13) | 5.76 (2.43) | 5.97 (1.94) | 2.55 | .091 | – | – |
| Personal control | 4.28 (2.49) | 5.14 (2.12) | 5.97 (2.02) | 10.52 | .000 | T1<T2; T1<T3 T2<T3 | 0.35 |
| Treatment | 6.90 (2.62) | 6.72 (2.54) | 7.09 (2.04) | 0.48 | .618 | – | – |
| Identity | 6.57 (1.85) | 5.99 (2.19) | 5.95 (2.21) | 1.35 | .270 | – | – |
| Concern | 8.12 (1.44) | 7.53 (2.07) | 6.72 (2.03) | 9.17 | .001 | T1>T3 | 0.32 |
| Coherence | 6.35 (2.63) | 6.77 (2.45) | 6.75 (1.88) | 0.34 | .710 | – | – |
| Emotional | 7.17 (1.96) | 6.52 (2.18) | 6.38 (2.28) | 4.21 | .022 | T1>T2 | 0.18 |

*Table 5*
Patients means and standard desviations for the measures at baseline (T1), post-interventions (T2) and at three months follow up (T3)(Carers CCSTW programme)

| | Baseline T1 M (SD) | Post-Intervention T2 M (SD) | Follow-up T3 M (SD) | F | p | Bonferroni post-hoc/ | Effect Size ŋ |
|---|---|---|---|---|---|---|---|
| HAD: | | | | | | | |
| Anxiety | 10.83 (3.99) | 11.16 (5.75) | 7.13 (5.09) | 5.84 | .010 | T1>T3 | 0.38 |
| Depression | 7.35 (4.82) | 7.92 (5.98) | 4.66 (3.71) | 4.95 | .010 | T1>T3 | 0.32 |
| GHQ-12 | 20.52 (8.28) | 17.30 (11.89) | 11.92 (8.32) | 26.73 | .000 | T1>T3 | 0.73 |

in nutritional difficulties between T1 and T2, and T1 and T3 (ŋ = 0.81) and in guilt and isolation subscales (ŋ = .16; ŋ = .14).

Lastly, carers were also asked about their illness perception. While the perception about identity, duration of the illness, coherence and treatment control remained unchanged throughout the study, the perception of personal control showed a significant increase from T1 to T3 (ŋ = .35) and the perception of illness consequences (ŋ = .93) and concern (ŋ = .32) presented a significant decrease from T1 to T3.

Changes in patient outcomes are shown in table 5. Psychological distress (GHQ-12) showed a significant decrease from T1 to T3 (ŋ = .73). Both, anxiety and depression (HADS) showed a significant reduction from T1 to T3 (ŋ = .38; ŋ = .32 respectively).

*Psychoeducational programme: changes in carers and patients*

In table 6 we present the means and standard deviations for the measures at baseline (T1), post- workshops (T2) and at three months follow-up (T3) for this group of carers.

Psychological distress (GHQ) and depression (HAD) decreased in a similar way to the CCSTW group (ŋ = .38; ŋ = .48 respectively). Anxiety also revealed a statistically significant reduction from T1 to T3 (ŋ = .30).

Respect to expressed emotion, emotional over-involvement also decreased (T1 > T2 > T3 ŋ = .63) as did criticism (T1 > T2 ŋ = .33), which revealed a significant reduction over time.

Respect to accommodation and enabling behaviours, carers' level of avoidance and reassurance seeking revealed a significant

*Table 6*
Psycho-educational programme: means and standard deviations for the measures at baseline (T1), post- intervention (T2) and at three months follow-up (T3)

| | BASELINE T1 M (SD) | POST-INTERV T2 M (SD) | FOLLOW-UP T3 M (SD) | F | p | Bonferroni post-hoc | Effect size ŋ |
|---|---|---|---|---|---|---|---|
| HAD | | | | | | | |
| Anxiety | 10.25 (4.27) | 7.84 (4.20) | 7.73 (4.96) | 4.73 | .020 | T1>T2 T1>T3 | 0.30 |
| Depression | 7.29 (4.09) | 5.42 (4.80) | 5.88 (4.25) | 10.33 | .001 | T1>T2 T1>T3 | 0.48 |
| GHQ-12 | 14.79 (6.35) | 10.92 (3.92) | 11.53 (5.03) | 5.71 | .010 | T1>T2 T1>T3 | 0.34 |
| FQ: EOI | 17.97 (6.08) | 15.18 (6.60) | 14.43 (5.50) | 17.89 | .000 | T1>T2 T1>T3 | 0.63 |
| FQ: CC | 10.98 (5.17) | 8.68 (4.22) | 9.25 (5.68) | 5.46 | .012 | T1>T2 | 0.33 |
| LEE Attitude illness | 1.11 (1.62) | 0.54 (0.72) | 1.08 (1.41) | 4.07 | .031 | T3>T2 | 0.27 |
| Intrusive | 2.91 (2.11) | 2.29 (1.84) | 2.29 (2.20) | 3.24 | .060 | – | –– |
| Hostility | 2.21 (2.04) | 2.04 (1.84) | 1.09 (1.03) | 6.15 | .008 | T1>T3 T2>T3 | 0.36 |
| Tolerance | 3.59 (2.28) | 2.23 (1.85) | 2.43 (1.64) | 7.19 | .004 | T1>T2 T1>T3 | 0.41 |
| Total | 8.91 (5.01) | 6.25 (4.33) | 6.69 (4.65) | 4.65 | .020 | T1>T2 | 0.32 |
| AESED Meal ritual | 3.06 (4.55) | 2.58 (4.26) | 1.73 (2.51) | 3.24 | .060 | – | – |
| Control fam | 12.52 (6.87) | 9.90 (6.59) | 9.66 (6.54) | 4.39 | .026 | T1>T2 | 0.31 |
| Reassurance | 9.20 (7.22) | 6.56 (4.29) | 4.60 (3.41) | 4.95 | .017 | T1>T3 | 0.31 |
| Turning | 1.47 (2.62) | 1.37 (1.77) | 1.67 (2.57) | 0.39 | .682 | – | – |
| Avoidance | 12.58 (8.7) | 9.96 (7.07) | 9.27 (5.05) | 3.83 | .037 | T1>T3 | 0.18 |
| Total | 37.82 (19.06) | 25.32 (16.28) | 22.93 (14.62) | 9.59 | .001 | T1>T2 T1>T3 | 0.50 |
| EDSI Nutritional | 10.90 (6.32) | 7.03 (5.00) | 6.21 (4.37) | 11.05 | .001 | T1>T2 T1>T3 | 0.51 |
| Guilt | 8.28 (5.37) | 6.21 (5.11) | 5.37 (5.15) | 5.30 | .013 | T1>T2 T1>T3 | 0.33 |
| Dysregulated | 2.79 (3.19) | 2.48 (2.60) | 2.80 (2.54) | 0.21 | .809 | – | – |
| Isolation | 7.92 (4.27) | 6.33 (4.56) | 5.47 (4.00) | 7.25 | .004 | T1>T3 | 0.40 |
| Total | 30.20 (15.55) | 22.56 (13.97) | 17.94 (13.43) | 9.46 | .001 | T1>T2 T1>T3 | 0.48 |
| BIPQ Consequences | 7.19 (2.12) | 5.43 (2.98) | 5.31 (3.04) | 6.95 | .004 | T1>T2; T1>T3 | 0.38 |
| Duration | 6.11 (2.44) | 5.82 (1.97) | 4.95 (2.48) | 3.64 | .043 | T1>T3 | 0.25 |
| Personal | 4.73 (2.28) | 5.69 (2.26) | 6.44 (2.14) | 5.51 | .011 | T1<T3 | 0.33 |
| Treatment | 7.25 (2.18) | 7.51 (1.79) | 7.63 (2.02) | 0.38 | .688 | – | – |
| Identity | 7.11 (2.09) | 5.56 (1.93) | 6.10 (2.74) | 7.30 | .003 | T1>T2; T1>T3 | 0.39 |
| Concern | 8.43 (2.09) | 6.86 (3.24) | 6.67 (2.70) | 22.38 | .000 | T1>T2; T1>T3 | 0.67 |
| Coherence | 7.03 (1.83) | 6.60 (1.70) | 7.12 (1.78) | 1.70 | .206 | – | – |
| Emotional | 7.49 (2.40) | 6.25 (2.85) | 5.70 (3.18) | 6.45 | .006 | T1>T2 T1>T3 | 0.37 |

reduction over time (T1 > T2 ŋ = .31; T1 > T3 ŋ= .31). The total score for accommodation and enabling behaviours (AESED) showed a significant decrease from T1 to T2 and from T1 to T3 (ŋ = .50).

In perceived difficulties participants experienced with the person they cared for, there was a significant reduction in nutritional difficulties and guilt over time, and in isolation from T1 to T3 (ŋ = .51; ŋ = .33; ŋ = .40 respectively). Total score of the EDSIS presented a significant decrease from T1 to T2 and from T1 to T3 (ŋ = .48).

Finally, the results in carers' illness perception showed a significant decrease in consequences, concern, identity and emotional representation over time, while the perception about coherence treatment control remained unchanged throughout the study. Personal control presented a significant increase over time.

There were no significant changes in patients in psychological distress, anxiety and depression.

*CCSTW versus Psychoeducational programme*

We compared the measures of the two groups at baseline (T1), post- workshops (T2) and at three months follow-up (T3) using independent samples median tests. No significant difference was found between the two groups at any time point.

## Discussion

The general aim of this research was to conduct a pilot study to measure the effectiveness of the CCSTW on the outcomes of Spanish carers. The findings of this study are consistent with previous research where it was found that participation in intervention programmes for carers significantly decreases the levels of expressed emotion, psychological distress and perceived carer burden (Hibbs et al., 2015; Pepin & King, 2013; Sepúlveda et al., 2008a; 2010).

Regarding the results of CCSTW, although anxiety did not change there were small reductions in depression, psychological distress and burden. This concurs with previous work using interventions for carers (Sepúlveda et al., 2008a; 2010; 2014). In terms of care giving behaviours there was a significant decrease in expressed emotion, in the level of emotional over-involvement over time and a smaller reduction in critical comments and hostility. There were also small reductions in accommodation and enabling behaviours.

Another variable included for the first time in an assessment after participation in these workshops was illness perception. There was a decrease in the carers' perception about how the disorder affects their lives and their concerns and an increase in the perception of personal control in relation to the disorder. In the literature, carer's lower perception of consequences, duration and concern, and a greater perception of personal control have been related to better outcomes in patients (Quiles, Weinman, Terol, & Beléndez, 2009).

The psycho-educational programme was also effective in decreasing levels of depression, expressed emotion, carers' perceived burden and in accommodation and enabling behaviours. With respect to illness perception, as in the previous workshops, after participation in the psycho-educational programme, there was a significant reduction in carers' concern, with a large effect size. Their perception of how the illness affected them emotionally and their identity with the illness also decreased significantly.

Thus, both intervention programmes showed an improvement in wellbeing indicating a benefit from the training with little differences between the forms of the intervention. No significant difference was found between the two groups. However, it should be noted that in contrast to the psycho-educational programme, the CCSTW did not decrease patients' level of anxiety, and although it did decrease depression and psychological distress, it did so with a low effect size. Nevertheless, it is important to consider that the psycho-educational programme included two sessions which directly dealt with carers' distress/anxiety. As well as this, they were taught relaxation strategies and the identification and restructuring of distorted thoughts. All of this could have contributed to a decrease in psychological distress in these carers in contrast to those who had participated in the CCSTW. In this sense, it would be of interest to include these contents in the CCSTW programme so as to help carers improve their levels of anxiety, depression and distress. There was also a lower decrease in accommodation and enabling behaviours in the CCSTW in contrast to the psycho-educational programme. One possible explanation for this result is that the psycho-educational programme included a problem solving session, where carers frequently presented solutions and were taught how to resolve situations that involved accommodating attitudes. These results suggest that perhaps the content and development of CCSTW needs to be changed in order to target these variables in greater depth.

The second objective of this study was to analyse whether and how the participation of the carers in these programmes affected the patients themselves. Given the small sample size, the results are exploratory. Anxiety, depression and psychological distress decreased in patients allocated to the CCSTW intervention. These results are consistent with the cognitive interpersonal model that suggests that when carers cope with the problem better they react with less expressed emotion, and this has beneficial impacts on the patient's symptomatology itself (Treasure & Palazzo, 2016; Treasure et al., 2007; 2008). In contrast the patients experienced smaller reductions in depression, anxiety or psychological distress when their carers took part in the psycho-educational programme.

Despite evidence that both programmes had positive impacts on carers' interactions with their loved ones, some limitations must be considered when reviewing the results of this study. The size and heterogeneity of the sample and the lack of a control group mean that the results should be interpreted cautiously. In the absence of a control group, it is possible that the improvements in the experience of care giving, expressed emotion and patients' psychological distress were merely spontaneous changes over time or that they resulted from non-specific effects such as attention and support rather than the procedures taught in the workshops. The differences in the time frame in which the workshops are held could be the reason why the psycho-educational programme response was much lower. Another limitation was the missing data in both groups; although we used models that accounted for this, it may limit the generalizability of the findings.

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